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ABSTRACT

This study analyzed the goals statements on Individualized Family Service Plans (IFSPs) or Individual Education Programs (IEPs) of 72 families in nine communities. The sample was drawn from communities of varying sizes in three states (Colorado, North Carolina, and Pennsylvania). Families were chosen to include children in 1-year age groupings and to maximize the level of disability complexity, race, and income differences. Goals were categorized by three raters into eight child-based goals: fine motor, gross motor, cognitive development, speech/language, psycho-social, self-help, sensory, and other. In addition, nine family goals were categorized: child-based intervention/service, medical/diagnostic information services, respite, support/counseling, basic needs, program participation/service coordination, family enrichment, transition, and other. Case study interviews and focus group discussions were held with the families. The major finding from the analysis of IFSP and IEP goals and the interviews was that goals and services were primarily child focused, with relatively few family goals or services designated, despite the recognized importance of a family-focused approach. Focus group results suggested that one reason for the lack of family goals may be a reluctance by service providers to intrude upon the private life of the family. Improved training of service providers is suggested. Tables detail the analysis of goals. (Contains 35 references.) (DB)

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Planning for Young Children With Disabilities and Their Families: The Evidence from IFSP/IEPs

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An Institute for the Study of Education, Health Care, & Social Service Utilization of Infants, Preschool Children, and Their Families

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Planning For Young Children With Disabilities And Their Families: The Evidence From IFSP/IEPs

James J. Gallagher

The complex relationships between service provider and client have been a topic of clinical discussions and scientific inquiry for many years (Meisels & Shonkoff, 1990: Bryant & Graham, 1993). How does one assist the family to cope effectively with the varied challenges of having a child with disabilities in ways that strengthen and empower the child and family rather than make them more dependent on outside help (Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993; Rosenkoetter, Hains & Fowler, 1994)? One of the solutions proposed to this question has been to design public policy by federal agencies that mandated parental participation in the development of the intervention plans for their own child (Johnson, McGonigel, & Kaufman, 1989; Burnim, 1990).

One of the specific strategies designed to aid the family to become a significant factor in the planning for their own child, has been the Individual Education Program (IEP) which was mandated for all children with disabilities as part of the Education for All Handicapped Children Act of 1975 (PL 94-142), now the Individuals with Disabilities Education Act (IDEA). The IEP was one of six major mandates of that law and was proposed, in part, to help redress the relatively weak position of power and authority of the parent in relationship to the professional (Gerardi, Grohe, Benedict, & Coolidge, 1984; Valentine & Stark, 1979; Zigler & Anderson, 1979).

Each Individual Education Program (IEP) was supposed to evolve from a multidisciplinary discussion of the needs and strengths of the child in question, with the

parent or parents playing a significant role in the design of the document. The required components of each IEP are as follows:

- present level of educational performance
- annual goals and instructional objectives
- Specific educational services to be provided
- extent to which the child can participate in regular education program
- projected date and duration of services
- objective evaluation procedures and criteria
- schedule for annual review

From the beginning, the IEP was a source of professional controversy with various strengths and weaknesses being highlighted through a wide variety of studies. Gallagher and Desimone (1995) reviewed the literature on the IEP which revealed a combination of strengths and weaknesses for the process. The strengths of the procedures were identified as encouraging better relationships between teacher and family (Goodman & Bond, 1993), creating a better understanding on the part of the family about the nature of their child's program (Say, McCollum, & Brightman, 1980), and providing continued information to parents on academic progress. These results seem to suggest that some of the original goals of the IEP had been achieved.

However, there also have been a wide variety of critical articles that make it clear that the IEP process often does not fulfill its promise. Some of the more serious issues noted were poorly written goals and objectives (Lynch & Beare, 1990), missing data that should be in the IEP (Smith & Simpson, 1989), no link between goals and program, no follow-up, and so on (see Gallagher & Desimone, 1995). These findings

have led many educators to believe that the IEP is often paperwork with no meaning, consuming time to no good purpose, lacking support from other professionals, and ignoring significant parent involvement.

Despite the ambivalent record of the IEP, the public policy benefits of individual planning were considered important enough to include a similar program in the legislation for infants and toddlers with disabilities. This time the process that was mandated was called the Individualized Family Service Plan (IFSP), a component of Part H of Public Law 99-457, now included in the Individuals with Disabilities Education Act (IDEA). By now, there has been a realization that the process of creating a plan may be as important as the product in strengthening the role of family participation in the child's program (Bailey, Buysse, Edmondson, & Smith, 1992; Bailey, Winton, Rouse, & Turnbull, 1990; Deal, Dunst & Trivette, 1989; DeGangi, Royeen, & Wietlisbach, 1992).

Gallagher and Desimone (1995) provided recommendations from their review of IEP studies indicating how the IFSP procedures might be modified to meet the objections to the IEP process. Among these recommendations were (1) that there be specific preparation for the IFSP session for both families and professionals, (2) a greater recognition of the role that time pressures play on the professionals in producing less than satisfactory plans, and (3) a periodic mandatory review to demonstrate that the IFSP is, and should be, a living and dynamic document that should be expected to change as circumstances warrant.

The Early Childhood Research Institute on Service Utilization (ECRI:SU) has designed an extensive research program to determine factors that may be influencing

the delivery of services to young children with disabilities and their families (Harbin & Kochanek, 1992). The major question addressed in this overall research program was, 'What factors influence the type and amount of service delivery to young children (birth to five) with disabilities and their families?' (Harbin & Kochanek, 1992). This study reported here is one part of that research program.

The purpose of this study was to analyze the goals statements produced from discussions involving 72 families, and the professionals serving their child, on either the Individualized Family Service Plan (IFSP) or the Individual Education Program (IEP) and to examine changes in these individual plans over time. The current study attempts to discover the type and amount of goals generated by this process for both the IFSP and IEP for these young children with disabilities. These families were also part of a major case study project being conducted by McWilliam and his colleagues (McWilliam, Tocci, & Harbin, 1995; McWilliam, Tocci, & Harbin, 1997; Tocci, McWilliam, Sideris, Melton, & Clarke, 1997).

METHOD

SAMPLE

The current sample of 72 young children with disabilities and their families were drawn from three communities of varying size in each of three states: Colorado, North Carolina, and Pennsylvania (Harbin & Kochanek, 1998). These states were chosen for the research institute program for their diversity of service programs and differing administrative organization. The size of the communities varied because of the assumption that patterns of service delivery might differ on that factor.

The communities were identified by state administrators as providing exemplary service delivery to this population. From all of these communities, 300 families were identified as a purposive sample chosen to maximize diversity in race, income, intensity and type of disabilities, and needs of families (Knapp, 1995).

From this sample of 300 families a panel of seventy-two families were chosen for case study, eight in each of the nine communities. These families were selected by the ages of the child. Within each community there were two families with a child under 1, two families with children in ages 1 - 2, etc. Within those age divisions, purposive selections were made to maximize the level of problem complexity, race, and income differences. Children and families were sought to maximize diversity of these characteristics so that ECRI:SU would be able to study the variety of services being delivered. It is this sample of 72 families that formed the base of the current study.

Measurements

The IFSPs and IEPs used in the present study were those obtained from the nine communities for these 72 case study children and their families in the basic study. Each of the states had slightly different recommended formats for how these documents would be developed and displayed and the local communities also produced minor variations on the formats. Whatever the modest differences in format, each state's IFSPs and IEPs contained a major section on goals statements, and it was these goal statements that were analyzed in the present study.

The goals on the IFSPs and IEPs were categorized according to a scale developed by Bailey, Winton, Rouse, and Turnbull (1990) that divides the goals into two major categories, Child Goals and Family Goals (see Table 1).

Under Family Goals were placed any goals requiring the action of some family member(s), or any action intended to benefit a family member(s) other than the child with a disability. Such goals would include the seeking of respite care, social support through counseling, seeking to increase family participation with the treatment program, seeing to it that the family had its basic needs of food, shelter, and clothing met, etc.

The Child Goals were statements in which the desired outcome was a change in the child with a disability. Such subcategories as Gross Motor Skills, Cognitive Development, Psychosocial Development, Self Help, etc. were included under Child Goals (see Table 1).

PROCEDURE

Signed permission slips were obtained from the parents to allow for access to the child's IFSP or IEP. The documents were copied and the copies forwarded to the author for analyses. Another set of IFSPs not included in the study were used to allow raters to practice categorizing the goals using the Bailey, et al. (1990) system. When the percentage of agreement between three raters exceeded 85%, the IFSP/IEPs for the case study children and families were coded according to the Bailey, et al. Goal Scale noted earlier (see Table 1).

Two of the three raters coded each document and then compared their

Table 1

Categorization of IFSP Goals: Child and Family

Child Goals

Any goal in which the desired outcome was a change in the child with disability.

1. Fine Motor
2. Gross Motor
3. Cognitive Development
4. Speech and Language Development
   Receptive Language Skills
5. Psycho-Social Development
6. Self-Help
7. Sensory Development
8. Other

Family Goals

Any goal requiring the action of some family member(s), or intended to benefit a family member (s) other than the child with a disability.

1. Child-based Intervention/Service
2. Medical/Diagnostic Information Services
3. Respite
4. Support/Counseling
5. Basic Needs
6. Program Participation/
   Service Coordination
7. Family Enrichment
8. Transition
9. Other

Source: Bailey, D., Winton, P., Rouse, L., & Turnbull, A. (1990). *Family goals in infant intervention: analyses and issues.* Journal of Early Intervention, 14 (1), 15-26.

judgments. When there was a difference in the classification by judges for a particular goal statement, a consensus was achieved in a meeting with the three members of the project staff. These coded ratings were then placed in a computer file for further potential analysis.

A second question was raised about the nature of the changes in individual planning over time. Would there be a shift in goals over time and over changes in programs? Consequently, a second request was made of the programs for an additional IFSP or IEP that would then be compared with the original goal statements. The vast majority of these were collected one year later but a few had a longer time interval from the original.

A variety of factors conspired to reduce the sample for the second analysis. Some of the families moved away, some children aged out of the program and others were not accessible. Therefore, IFSP and IEPs for a total of 39 children were analyzed using the same Bailey et al. system that had been used in the earlier analysis. A similar procedure for dealing with disagreements was followed as was used in the original analysis. An 85-90 percent agreement in ratings prior to consensus discussions was consistent over the two analyses.

DATA ANALYSIS

The number and type of goals for each child and family, and for each community, were tabulated, summed, and entered into a data file. Means and standard deviations were calculated and are presented here.

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RESULTS

The Results section presents a description of the number and type of goals selected for this sample of children with disabilities and their families. The results are separated by size of community.

The total number of goals listed for the seventy two children in our sample was 828 or approximately 11 goals per child. There were 115 family goals generated, about 14% of the total number of goals contained in these 72 documents (see Figure 1 and Figure 2). This represented an average of between one and two family goals per child, but such distribution was not a consistent one, either by child or community. Half of the children with IFSP/IEPs did not have a single family goal listed on their individual plan.

The ratio of family to child goals appeared quite low considering the current emphasis on family focus (6 child goals per 1 family goal). The actual family involvement in the goals that was anticipated was even lower than that ratio. Two of the family goal categories: providing the family with information on services, and giving medical and diagnostic information to the family, did not require any extensive family interaction with service personnel (Bailey, et al., 1990). These two categories, comprised 9% of the 14% total family goals.

Child Goals. Figure 1 shows the percentages of the types of child goals that were included in IFSP and IEPs in the present sample. The emphasis of child goals in the gross motor and fine motor development noted here probably is accounted for by the young age of many of the children in the sample, plus the presence of some degree of motor impairment in many of the children with disabilities in this sample.

Figure 1

Child Goals by Community Size

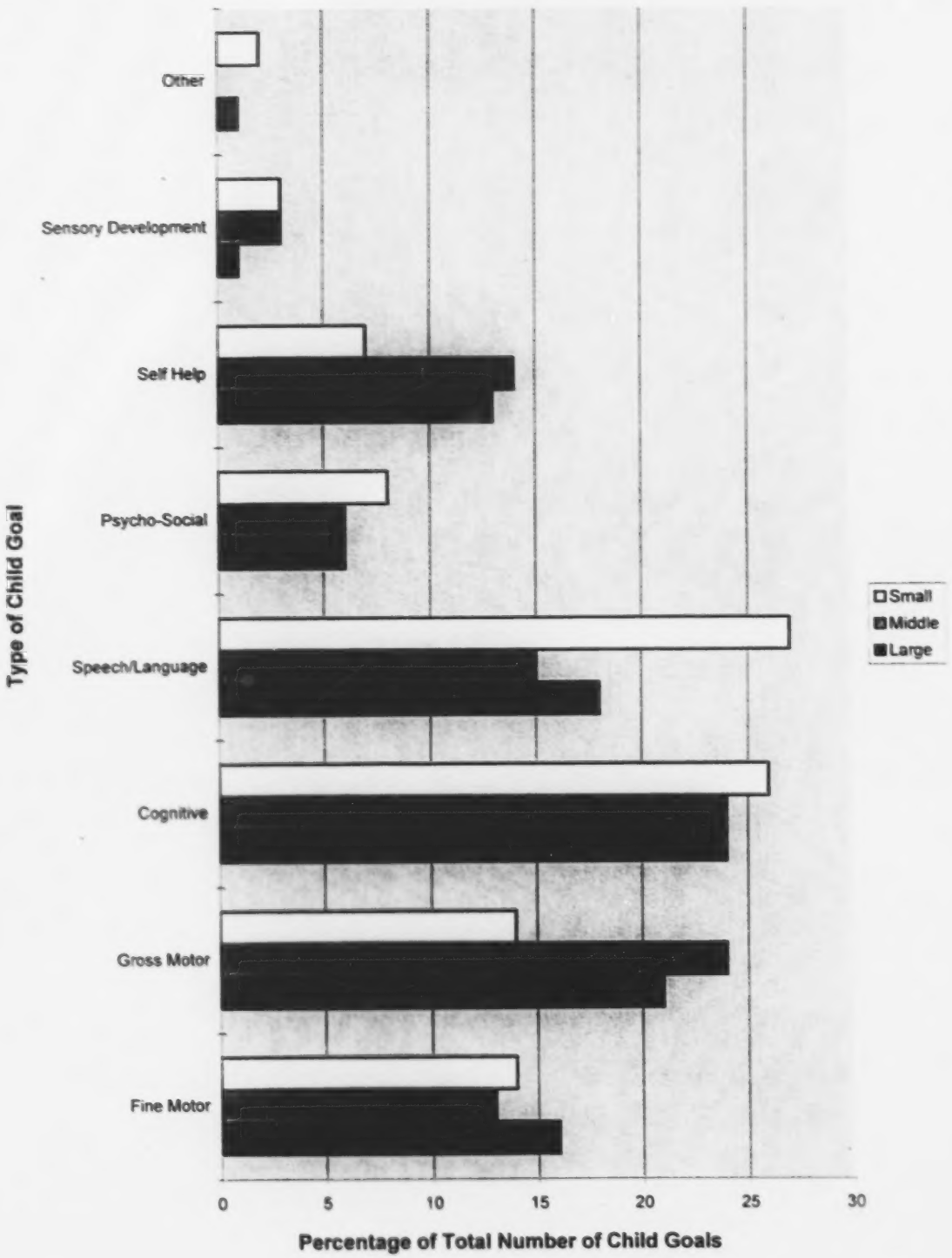
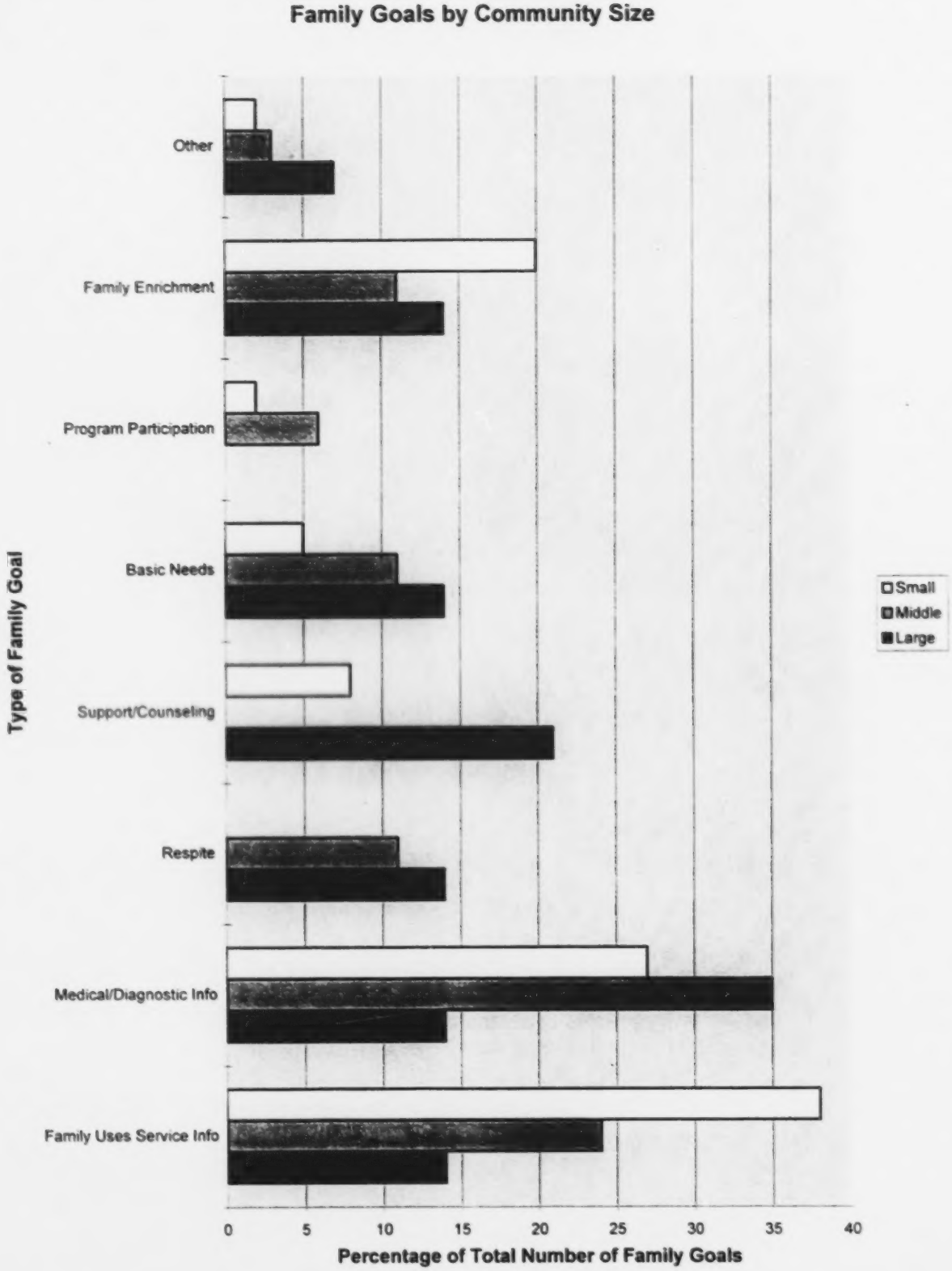


Figure 2


Family Goals by Community Size
Other
Family Enrichment
Program Participation
Basic Needs
Support/Counseling
Respite
Medical/Diagnostic Info
Family Uses Service Info
Type of Family Goal
Small
Middle
Large
0
5
10
15
20
25
30
35
40
Percentage of Total Number of Family Goals

The major emphasis on cognitive and child speech/language goals fits the traditional goals for interventionists at this development level. It also fits the traditional training of the early intervention specialists in these programs. There are proportionately fewer child goals focusing on sensory development, the psycho-social development of the child, and on the self-help dimension, suggesting a lesser emphasis on these goals. The lack of emphasis on social goals and objectives has been noted by others as well (McCollum, 1995; Michnowicz, McConnell, Peterson, & Odom, 1995).

Family Goals. Figure 2 provides a similar portrait of how the total number of 115 family goals were assigned, by size of community. As noted earlier, providing information on the nature of the child's disability and the whereabouts of services made up the larger proportion of family goals. Respite care and counseling received some attention together with some family enrichment and support. In families of very low income, attention was paid to the basic needs of food and shelter as a foundation from which any assistance to the family should start. Almost entirely absent however, were goals of increasing family participation in the intervention program itself.

Related Factors

Another question posed in this study was whether the type and amount of goals in the IFSPs and IEPs were linked to variables such as age and the type of service provision being provided.

Age and Type of Plan

A clear delineation in the current sample can be made between IFSPs (below age 3) and IEPs (above age 3). When the children reach the age of 3 they become the responsibility of the education department in the state and often meant changing the venue of the service as well as the type of individual plan. It also represents an interesting dichotomy in that there is a presumed mandate for the IFSPs to pay attention to the family. The IEP has no such requirement, even though the needs of the family have certainly received much attention in the special education literature.

Table 2 shows the means and standard deviations of child and family goals by IFSP and IEP. As can be seen, child goals predominated in both situations but there was a statistically significant difference ($p. < .05$) in the number of family goals between the types of plans but no such difference in the number of child goals. There was less than one family goal per IEP, but more than two family goals per IFSP.

The difference in the format and expectations of IEPs and IFSPs preclude a simple conclusion as to what was responsible for this difference in written family goals. It is clear, however, that there were few family goals written in either IFSPs or the IEPS.

Distribution of Child and Family Goals by IFSP and IEP

Table 3 provides the mean number of goals in each of the major categories in the Bailey, et al. (1990) system for the first and second planning sessions for the thirty nine students for whom data were available. As can be seen from Table 3, the changes in the types of category used were rather modest and seem to reflect the

Table 2

Distribution of Child and Family Goals by IFSP and IEP

	N	*Child Goals*		*Family Goals*	
		Mean	σ	*Mean*	σ
IFSP	48	9.02	8.17	2.15	3.01
IEP	20	10.45	7.24	0.55	1.32
		† = .68 p = .50		† = 2.27 p = <.05	

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Table 3

First and Second Individual Plan Goals (N=39)

	First Plan		Second Plan	
Child Goals	M	σ	M	σ
Fine Motor	1.92	2.12	1.92	2.52
Gross Motor	2.25	3.51	2.15	2.49
Cognitive Development	3.10	2.55	4.36	3.93
Language Development	2.13	2.62	1.79	1.96
Psycho-Social Development	.90	1.39	1.43	1.81
Self Help	1.30	1.54	1.15	1.40
Sensory Development	.15	.36	.28	.64
Total	**11.76**	**8.79**	**13.28**	**7.70**
Family Goals				
Info-Child Intervention	.56	1.39	.38	.67
Info-Medical Services	.31	.57	.28	.65
Respite Care	.10	.31	.05	.22
Support/Counseling	.15	.67	0	0
Basic Needs	.15	.43	.10	.30
Program Participation	.05	.22	.10	.38
Family Enrichment	.33	1.34	.08	.48
Transition	.02	.16	.10	.38
Total	**1.69**	**3.11**	**1.10**	**1.65**

developmental growth of the child from one time to the next. There was a minimum of a year that had elapsed between plans and sometimes there was a longer gap.

There are more cognitive goals on average for the second individual plan than for the first (e.g., *will place objects in, on, under, beside on request; will divide pictures/objects into 3 simple categories with 80% accuracy*). Since many of these youngsters were at a developmental level of two years or under during the first planning period it would be expected that goals of cognitive development would play a larger role in the second plan with the children at a higher developmental level after a year or more passes.

Similarly, there was an increase in the number of goals for psychosocial development as the child matures into peer group activity (e.g., *will play cooperatively with peers; will be able to name and talk about her feelings*). On the other hand there is some decrease in the average goals for gross motor and language development. Such language, in the first plan, often meant that the child was being encouraged to state one word responses or to name various common objects. Now, at the time of the second plan, the 'language' is being combined with cognitive tasks and the child was being asked to use language as a component for solving cognitive tasks (e.g., *take part in reading by inserting words or phrases as stories are read with 80% accuracy*).

There is a reduction in goals promoting self help skills, reflecting again, that the children have now mastered some of the basic self help tasks such as feeding themselves, or mastering toileting skills, etc. and that the emphasis can now be placed on more developmentally advanced goals.

On the other hand, there were fewer family goals than in the first analysis. There was only an average of about one family goal per child in the second goal setting suggesting that this type of planning does not lend itself to family goal setting, even if such were desirable. Those family goals that were included in the second analysis were mainly the delivery of information to the family rather than an attempt to modify the family's circumstances directly (e.g., *service coordinator will provide family with some information about weight control; will assist family in public school placement*).

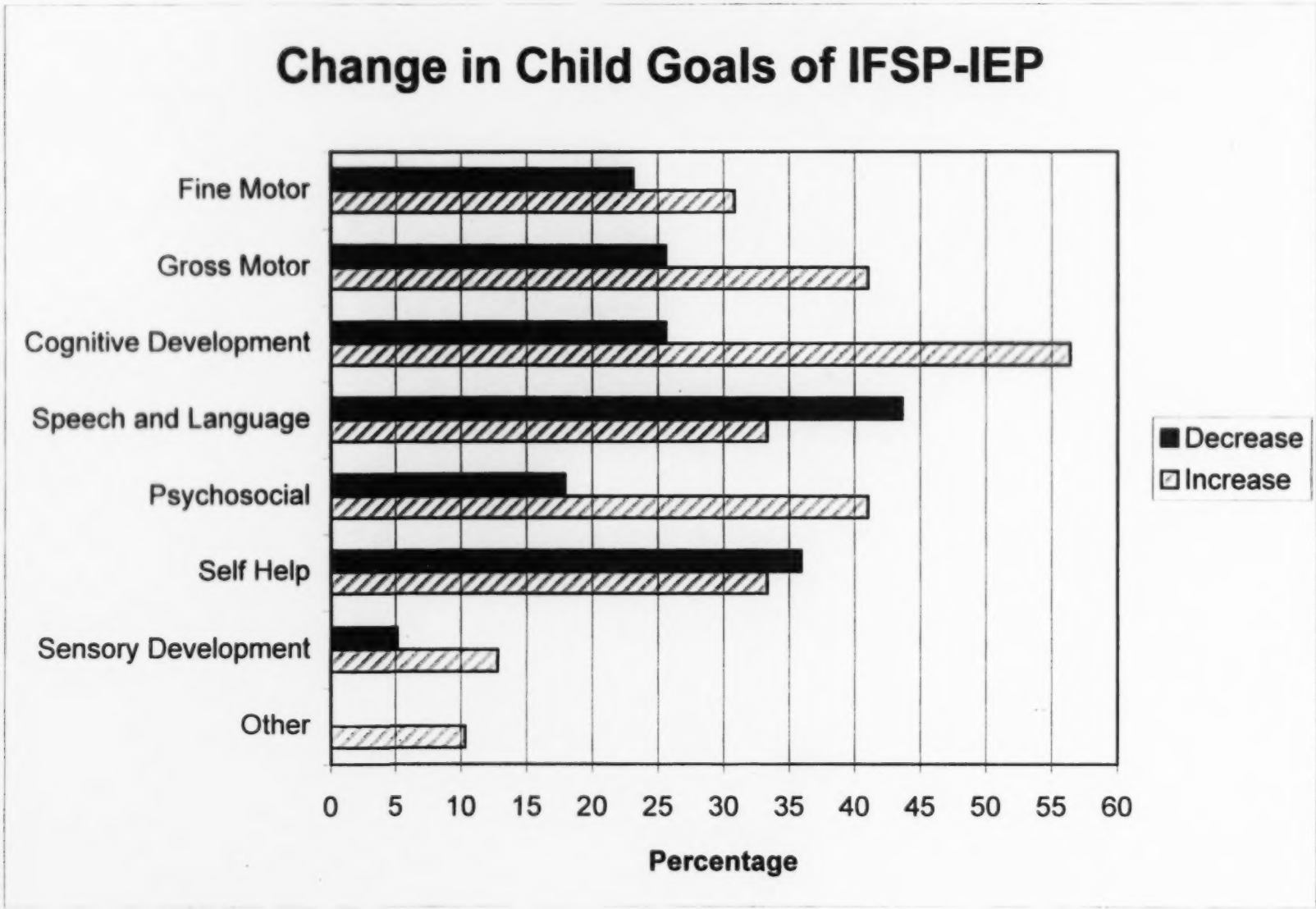
In the first analysis of IFSP/IEP planning only 12% of the total goals set were family goals. In the second analysis the number of family goals dropped to less than 8% of the total. Other data from the case studies and focus group interviews (McWilliam, Tocci, & Harbin, 1995; Gallagher, 1997) confirmed the relative lack of interest in family oriented goals for the families in this study.

Changes in Same Child

The above data reflect changes in a group of children. We wished also to determine the changes in goals for specific children. Figure 3 shows the results of child goals of individuals compared with themselves at two different points in time. For example, on the child goal of improving the fine motor skills twenty three percent of the sample showed fewer fine motor goals on the second analysis while 31% showed an increase in such goals. This would leave about forty six percent of the children who showed no change in the number of goals in this area from the first to second analysis.

Another change can be noted in goal three, cognitive development. Here 56% of the sample showed an increase in the number of cognitive goals while only 25%

Figure 3



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showed a decrease. Just as was indicated in the group data, the stimulation of cognitive development showed a strong increase over time, reflecting the greater maturing of the child and perhaps an attempt to help the child in his/her readiness for school.

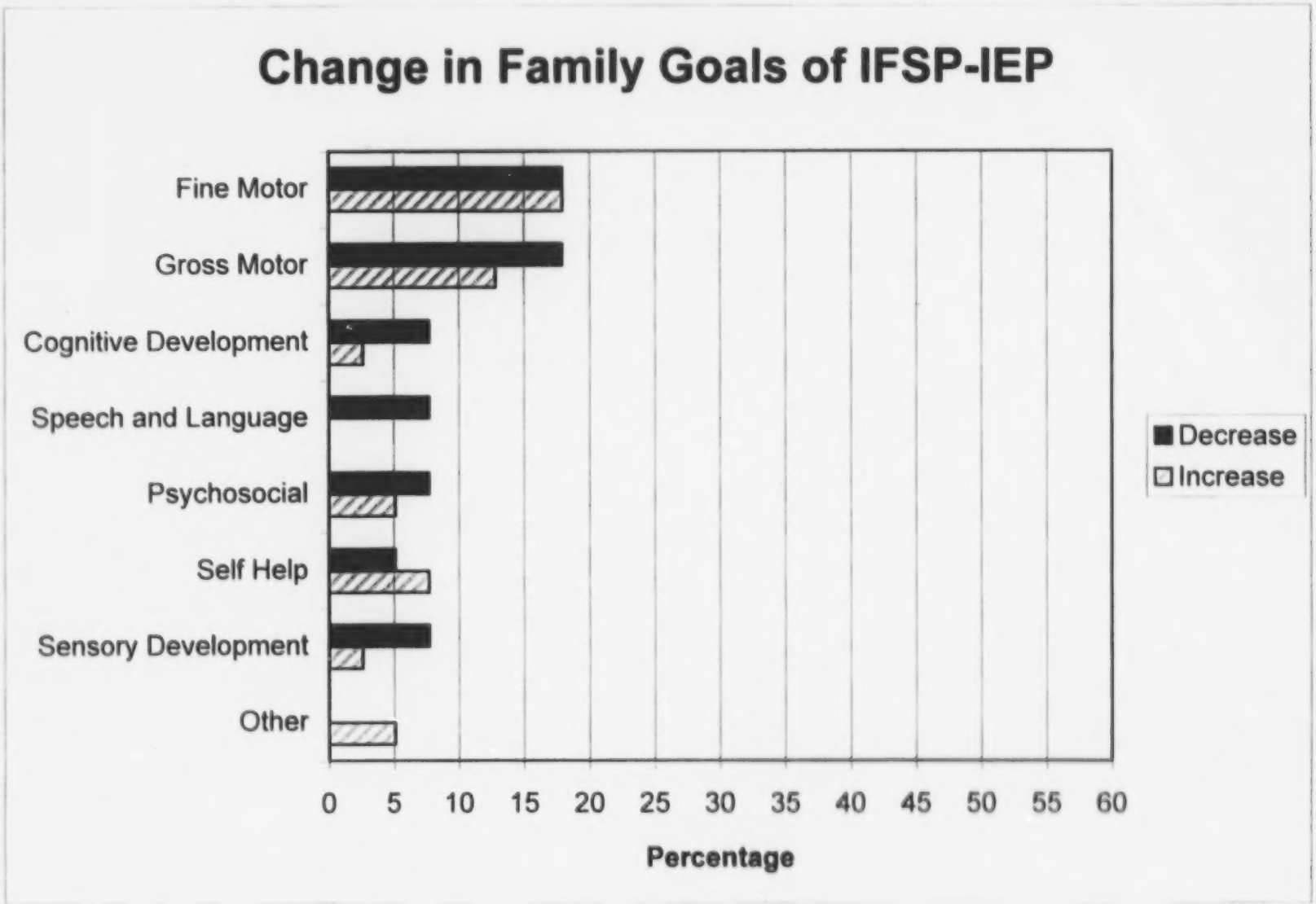
Another sharp increase in individual plans can be seen in category #5 psychosocial development. Forty-one percent of the children had an increase in psychosocial development goals as opposed to only 18% of the sample showing a decrease in such goals. Once again we can note a change in focus toward those skills typically developed in preschool settings with correspondingly fewer goals on self help or sensory development.

Overall, 67% of the children in this sample showed an increase in the number of goals included in their individual plans while only 20% showed a decrease reflecting a tendency for planners to consider a larger number of goals as children grew older.

Figure 4 indicates changes in the number and types of family goals from time one to time two of the individual plans. As Figure 4 indicates, there are only a few changes. Since there was a lack of family goals in both sets of individual plans there were no changes in the number of goals noted in the vast majority of cases.

In general, 28% of the individual plans contained a diminished number of family goals, while 23% showed an increase apparently representing no major shift, in contrast with the child goals where three times the number of children showed an increased number of goals on the second analysis.

Figure 4


Change in Family Goals of IFSP-IEP
Fine Motor
Gross Motor
Cognitive Development
Speech and Language
Psychosocial
Self Help
Sensory Development
Other
0
5
10
15
20
25
30
35
40
45
50
55
60
Percentage
Decrease
Increase

Changes in Individual Child Plans

Figure 5 contains a comparison of some of the goals that were noted in the first and second plans of selected children. There can be noted some obvious developmental progress over time with some of the children. For example, in the second plan, Edith will eat with a spoon with no trouble, whereas in the first plan the planners would be happy if she just held a glass in both hands.

Similarly, Ralph will now be involved in linguistically identifying opposites whereas previously he merely had a rudimentary vocabulary and Susie will move from one place to another instead of just being expected to stand unassisted.

At the same time these modest changes in these goals remind us how slow the progress is for many children. At a life period, during the preschool years, where the normal child shows enormous growth in vocabulary, thinking skills, and physical abilities the gains noted here must be agonizingly slow for parents eager to see their child grow up and perform as normal children.

Most of the youngsters in these programs have moderate to severe disabilities and while we can applaud their advances on one hand we realize that such children surely need continued special services if they are to participate meaningfully in public school elementary programs.

DISCUSSION

The analysis of the IFSPs and IEPs of a sample of seventy two preschool aged children with disabilities obtained from three different sized communities from three states has yielded several points of interest. First, there were found a limited number

Figure 5

Comparison of Individual Plan Goals from First to Second Plan

Child Name	First Plan	Second Plan
Ralph	Will increase his expressive vocabulary by one or more words or signs	Will identify/name 4 sets of developmentally appropriate opposites with 80% accuracy
Melinda	Will increase expressive/receptive language skills	Will increase her receptive and expressive language skills by identifying objects using pre-kindergarten concepts of size, shape, color, location, etc. 75% of the time
Susie	Will stand unassisted leaning against a table or chair	Will purposefully move from one place to another
Edith	Will hold a glass in both hands and drink	Will eat with spoon with little or no spilling
Brian	Will be able to adapt to 3 piece formboard reversal in 4 trials	Will divide pictures/objects into 3 simple categories with 80% accuracy
Donald	Will receive speech/language therapy at least once per month and will produce syllable strings with "b, m" at least 10 utterances/session for 2 consecutive sessions	Will increase ability to follow simple commands and will increase receptive vocabulary in prepositions, recognition of people, and common objects
Tam	Will imitate spontaneously 5 words	When given a set of 5 familiar objects, he will correctly identify each
Helga	Will give things to others upon request	Will point to or look at objects or people named

of family goals set despite many discussions in the field and literature of the importance of establishing a family focused approach.

There would seem to be several possibilities to account for these findings. One such possibility would be that there were strong interests and interactions with the family on the part of the service providers but that such interests were not reflected in the goals statements of the individual plans for the children. However, the data drawn from case studies in the same sample (McWilliam, Tocci, and Harbin, 1995) and from focus group discussions of family members and providers (Gallagher, 1997) confirmed a lack of family focused activities.

Another source of data on the children and families in the current study came from the case study interviews of these same 72 families. McWilliam, Tocci, & Harbin (1995) conducted in-depth interviews of the parents of the case study children whose IFSP/IEP findings were the source of the current data presentation. A semistructured interview protocol was followed and the transcripts of the sessions were coded and analyzed to determine whether services were predominantly child versus family oriented.

The findings from these interviews were that the services <u>were</u> primarily child focused and many parents reported that "family level concerns are their own business and they don't expect early interventionists to be involved in non child-related issues." McWilliam, Tocci, & Harbin (1995) speculated on some of the reasons for the lack of family focus in the 72 case studies and suggested that:

a) professionals feel they do not have time to spend on family level assessment and intervention

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b) some professionals might be overwhelmed at the expanded role inherent with a holistic, family empowerment approach

c) many professionals might have a limited understanding of family centered approaches (p.3.)

One possible explanation which emerged from the focus group discussions noted above was a reluctance on the part of the service providers to intrude upon the private life of the family unit. Many service providers seem to struggle with how far to go in interacting with the family in the interests of the child. The dividing line between helping and being seen as intruding seems to be a fuzzy one in the minds of many service providers and administrators.

If we wish to increase the family focused activity in these settings we will have to provide service providers with a clearer vision of that line of demarcation between what is acceptable family interaction, in terms of the needs of the family, as well as the needs of the child. We can note, as well, that the limited number of family goals may also be related to the limited professional preparation many of the service providers have had in working directly with family members as opposed to their children. Few of the current professionals involved with these families have had formal preparation in family counseling, for example. A strong case for more training of professionals in the use of the IFSP has been made by Farel, Shackelford, and Hurth (1997).

A certain degree of uncertainty with one's own capabilities in this area along with an already heavy set of responsibilities can allow the service provider to plead that they have "no time for family interactions." The introduction of Part H (now Part C) provisions for infants and toddlers increased substantially the number of families that

were seeking services for their child with disabilities (or "at risk" for disabilities in some cases). While the case load increased substantially, the number of service providers increased only marginally, putting additional pressure on the service programs.

In addition the goals for the children emphasized traditional developmental goals in the areas of motor development, and cognitive and language goals. Much less stress was placed on psychosocial goals possibly reflecting the professional training of the service providers. The modest changes from one year to the next in these goals for individual children remind us of the slow progress of children with moderate to severe disabilities and the need for a constant program for services for them as they enter public schools.

Certainly, we should pursue further what the nature of the forces are that appear to be at work in inhibiting more direct application of 'family centered' service delivery planning to families with children with disabilities.

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